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ABSTRACT

The partnership described focuses on a severe problem with environmental pollution at Akwesasne, the Mohawk reservation situated along the St. Lawrence River, at the juncture of New York, Quebec, and Ontario. Industries are located along the river and its tributaries and in past years have discharged PCBs (and other toxins) into the waterways in and near the reservation. The community residents are very concerned about the effects of the toxic intrusion into their previously harmonious relationship with the natural environment. Community members worry that Akwesasne children may have been exposed in utero from accumulated maternal PCBs, from being breast fed, or from their own diet or contact with the water or adjacent air. The study described concerns the effects of PCBs on the physical, sexual, cognitive, and social development of adolescents at Akwesasne. The research questions address the relationship between the adolescents' exposure to PCBs (assessed by diet history), body burden of particular congeners (types) of PCBs (assessed by blood analysis), and their physical, sexual, cognitive, and social/behavioral functioning. The collaborative process between the community members and the researchers is detailed, focusing on the three principles of respect, equity, and empowerment. (Contains 13 references.) (GCP)

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Partnership with a Native American community: A research team's perspective.

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Introduction

This paper is one of a pair describing an ongoing research study conducted in collaboration between scientists from the University at Albany and residents of the Akwesasne Mohawk nation. Our responsibility is to discuss the university research team's perspective on this collaboration. Alice Tarbell (1999) presents the community's perspective in a related paper.

The Problem

The focus of the partnership is a severe problem with environmental pollution at Akwesasne, the Mohawk reservation. Akwesasne is situated along the St. Lawrence river, at the juncture of New York, Quebec and Ontario. Industries, including a federally designated Superfund site and two state Superfund sites, are located along the river and its tributaries and in past years have discharged PCBs (and other toxins) into the waterways in and near the reservation.

PCBs (or polychlorinated biphenyls) are groups of man-made toxins escaping into the environment as a by-product of some industries. Their properties made them suitable for such purposes as insulators, coolants and lubricators in electrical equipment, as well as in adhesives, dyes, and hydraulic fluids, etc. Their production was banned in the USA in the 1970s, but they remain in the environment and the human food chain. In particular, PCBs accumulate in the fatty tissues of fish and consumers of fish. Fish consumption, placental transfer and breast feeding are the main ways that children become exposed. Residents in some communities are particularly vulnerable to the effects of PCBs either because of location or lifestyle. Their life near the waterways place the Akwesasne Mohawk residents at risk.

This is a particularly tragic situation for the Mohawks, as their tradition honors the waterways as the source of life. In regular ceremonies the Mohawks continue to thank the water, river life and game for providing and sustaining their life. As an example, when we were planning the research study, a team of researchers from the university visited the Akwesasne Mohawk Freedom School, where students are immersed in the Mohawk language. The school day opened and closed with the assembly of children thanking the elements and animals of nature for their contribution to the community life. Prominently featured was a mural centered around the river and the creatures and plants living nearby. Yet pollution may be depriving this generation of children of the nurturance provided by the river. It may also be interfering with the birthright that the community seeks to provide to the next seven generations.

The community residents are very concerned about the effects of the toxic intrusion into their previously harmonious relationship with the natural environment. They have shown themselves to be willing to modify their lifestyle because of fish advisories issued by the Environment Divisions of the St. Regis Tribe and Mohawk Council. Mohawk women's concern about whether they might be passing on their own accumulated PCBs and thus endangering their infants by breast feeding led to a series

of studies about the effects of PCBs on community members (Bureau of Environmental & Occupational Epidemiology, 1995; Fitzgerald, Hwang, Brix et al., 1992). They have created a Task Force on the Environment to gain and disseminate information, and initiate action, about environmental issues. The Task Force spear-heads the community in the research collaboration.

Community members worry that Akwesasne children may have been exposed in utero from accumulated maternal PCBs, from being breast fed, or from their own diet or contact with the water or adjacent air. Thus, the collaboration began with Mohawk concerns, and their desire for ecologically valid information to arrest the danger to their people and their traditions. The Task Force seeks information to assess the adolescents' development, inform interventions for the children, and inform action about the environment. University scientists were asked to help find this information.

The Research Study

The study in which we became partners concerns the effects of PCBs on the physical, sexual, cognitive and social development of adolescents at Akwesasne. We are now in the final year of the 5-year study that is funded by the National Institute of Environmental Health Sciences as part of the federal Superfund Basic Research Program. Dr. Lawrence Schell is Principal Investigator of the study, and the university person responsible for investigating the physical and sexual status of the adolescents. However, as this is a psychological forum, we will concentrate in this paper on the aspects of the study that we supervise concerning the psychological development of the adolescents.

Previous research has shown that children's physical and psychological health may be harmed by exposure to elevated levels of environmental PCBs, and that community concerns are warranted. Knowledge of the dangers first came from studies of children in Asia born to mothers who had been exposed accidentally to very high levels of PCBs in contaminated rice cooking oil (Chen, Guo, Hsu & Rogan, 1992; Chen, Yu, Rogan, Gladen & Hsu, 1994). Subsequent studies in the United States showed that negative effects followed from moderately elevated (Jacobson & Jacobson, 1996; Jacobson, Jacobson & Humphrey, 1990), and even background levels of environmental PCBs (Rogan & Gladen, 1985). Pre-natal, and sometimes post-natal, exposure has been implicated. Animal studies (Rice, 1998, 1999) confirmed the effects. Psychological effects shown in the human studies include reduced intelligence, memory deficits, altered activity level, behavioral problems, and some reading difficulties.

Our research questions address the relationship between the adolescents' exposure to PCBs (assessed by diet history), body burden of particular congeners (types) of PCBs (assessed by blood analysis), and their physical, sexual, cognitive and social/behavioral functioning.

School psychologists on the research team have selected the psychological assessment instruments which address community concerns, provide valid information for Native Americans, and target areas of functioning pinpointed by earlier research studies. Resulting areas assessed are cognition (assessed by the Woodcock- Johnson Tests of Cognitive Ability: Revised, and Ravens Standard Progressive Matrices), memory (assessed by the Test of Memory and Language), activity level and attention deficit (assessed by the Attention Deficit Disorders Evaluation Scale, Parent and School Versions), social behavior (assessed by the Conners Scales, Teacher and Parent forms) and academic functioning (as indicated on the school report card).

Community members have been trained in the administration and scoring of these psychological tests. Information is also gained about other factors (such as maternal cognition, diet, body composition, other chemical exposure) which might modify any PCB effects on the areas of functioning assessed.

Approximately 280 Mohawk adolescents (ages 10-16) and their mothers have already participated. Each participant receives a written report summarizing their performance on the psychological tests, and a personal conference if they request it.

Partners in the Collaboration

The two communities involved on the collaboration may be differentiated in a variety of ways. The most obvious is the distinction is between Native- American and non-Native. Although located between the United States and Canada, the Akwesasne Mohawk community is separated from these two countries by political, ethnic/racial, historical, and cultural factors. Differences are emphasized and maintained by ongoing economic/commercial and political factors and media reports of these. Forces within the Native community are attempting to nurture the Mohawk traditions, language and identity; these initiatives also reduce similarity with US and Canadian neighbors. Because of the various forces making cultural differences salient, Native and non-Native researchers must be continually alert to likely differences of custom and perception.

The ethnic division (Native American versus non-Native) coincides with several other ways in which the two communities could be differentiated, and which outline the perspectives to be reconciled in the collaboration. Thus there are ivory tower (university) scholars and community residents, researchers and subjects, experts and lay people, those driven by theoretical interests or by practical concerns, those seeking publishable data or usable knowledge. Not trivially, the two communities are separated by four to five hours of driving.

The communities contrasted in these fashions have been distanced traditionally by unconcern, mistrust and sometimes competing interests (Denner, Cooper, Lopez and Dunbar, 1999). Nevertheless, the particular research focus posed by the concerns at Akwesasne, provides us all with a stake in positive outcomes of the study.

Moreover, our outcomes are mutually dependent. Realization of this has enabled us to establish a workable, productive collaboration, a partnership. It has not all been smooth, and there have been problems to overcome. The collaboration has required patience, compromise and good humor. We will offer the perspective of the university researchers. Alice Tarbell, Chairperson of the Akwesasne Task Force on the Environment, will present the perspective of the Native-American community in a related paper (Tarbell, 1999).

As representatives of the university partners in the collaboration, we are a faculty member and graduate student in School Psychology at the University at Albany. Joan Newman specializes in child development. She looks to publications about this research project to advance her academic career. Mary Ellen Rougas is a doctoral student about to commence her final internship in a public school setting. A component of this research project will comprise her doctoral dissertation. We both share the Mohawks' concern for their children and their traditions. However, our traditions require that to provide knowledge for solutions to local Mohawk problems, we must draw on information provided outside the locality by previous research studies, using the university scientific tradition as a heuristic to gain knowledge. This is the perspective we bring to the collaboration.

The Collaborative Process

The Akwesasne Mohawk community is no stranger to research and university researchers. Alice Tarbell's paper (1999) will tell of some of their experiences in this regard. We have been surprised at the frequency of requests that are made to the community for permission to carry out research at the reservation. It has been clear to us from the start of our collaboration that the community has felt disappointed and even exploited by some of our predecessors. On the other hand, there have been some excellent relationships developed with researchers.

Based on their earlier experiences, good and bad, the Akwesasne Task Force on the Environment has created a research protocol setting out the principles of acceptable research processes on the reservation. The protocol emphasizes three principles: Respect, Equity and Empowerment. We endeavor to follow the principles to avoid adding to "successive layers of cultural insensitivity [that] accumulate and foster the persistence of the problem" (Rogler, 1999).

The principles of respect, equity and empowerment set the agenda for the accommodations that the Mohawk and non-Mohawk research partners must achieve. The same principles also define criteria by which our collaboration may be examined.

From our university perspective, how has the project progressed in relation to these three principles?

<u>Respect</u>

The collaborative endeavor demands several facets of respect. We must show respect for the points of view of our Mohawk collaborators; we expect respect for our own perspectives; finally we must show ourselves to be worthy of respect.

Respectful collaboration does not require elimination of differences. Respect demands that we recognize that each perspective has value, and that we can integrate the perspectives for mutual advantage. As university researchers, we value the traditions of the scientific method in establishing knowledge. Yet, Rogler (1999) suggests that these traditions can encourage cultural insensitivity, and can generate information that is irrelevant to a particular culture. To avoid this unsatisfactory outcome, we have tried to maximize the points in the research enterprise where the perspectives of the local community can be heard. Of course, the existence of the research project itself arose from the community. The outcomes (dependent measures) to be studied came from a combination of community input and previous research findings. We respected the community's concerns about bias in traditional cognitive tests, and chose instruments that are not associated with negative cultural and ethnic portrayals. We rewrote certain items in the interview schedules to represent local definitions of social class, and cultural affiliation. We accepted the community's aversion to formalized scrutiny of racial identity, and allowed self-definition of Native-American status. As a result, our sample contains some Mohawks who reside nearby, but not on, the reservation. After initial resistance, we also became persuaded by our Mohawk colleagues to accept volunteers, after being convinced that we would ultimately need all available and qualified adolescents in our sample.

The research process that has evolved from the collaborative relationship has some unusual features, resulting from compromise between the strengths of the traditional practices of the scientists and of the Mohawk community. For example, the organization of the research team is something of a compromise between the more hierarchical structure of the university community and the more shared decision making of the Mohawks. We originally tried to impose a community liaison person for the project, but found this to be ineffective. We now meet in large groups, all university and community researchers together to ensure successful communication.

The scientists have yielded certain roles to community members. We value the talents of community members and have trained Akwesasne residents to be our interviewers and testers. Direct contact with participants and schools is made by the community members of the research team. Testing and interviewing are performed by these community members, who lack formal psychological qualifications, and who are neighbors, friends and relatives of participants. This has advantages in recruitment. Any potential risks to standardization and confidentiality are eliminated by the evident respect shown by our interviewers for their fellow community members. Local interviewers also have sensitivity to local terminology, interaction patterns and body language. As one example, we found it necessary to modify training regarding the benefits of frequent eye contact between tester and adolescent, as our Mohawk testers educated us about the different messages conveyed by eye contact in their culture.

Respect is a two way process. We aim to show by our professional and personal behavior that we are worthy of the trust of the community. We believe that communication fosters trust. To trust us, the community members must know us. Therefore, we have found that it is necessary to devote considerable time to meetings, phone calls, Email and faxes. We have presented a workshop at Akwesasne, and spent summers in camp with community members.

However, respectful collaboration is not just comfortable communication or interaction. As we have said, it requires sharing of strengths and differences for mutual gain. We believe that some aspects of what we have to offer the partnership (i.e. our scientific research tradition) cannot be compromised. Therefore, despite the above accommodations, we have continued to emphasize standardized test procedures, the importance of gaining a sample large enough to provide statistically significant findings before drawing conclusions, and maintenance of the participant criteria for inclusion in the sample (thus not accepting siblings nor targeting children with known developmental difficulties). Our Mohawk researchers have accepted, honored and (we believe) valued these principles. We believe that the steady rate of volunteering to participate in the study indicates that people respect us and what we have to offer (as well as reflecting their hope that answers will be provided for community concerns).

Equity

Collaboration implies acknowledgment of equity among participants; acknowledgment that all are stakeholders; that all have a crucial role; that all are interdependent. Our interdependence comes from the fact that we all need a positive outcome from the research. In other words, we all need valid knowledge about the effects of PCBs on the Akwesasne adolescents, although the purpose to which we will put this knowledge may differ.

Collaboration involves "give" and "take" in equitable proportions. In exchange for the expertise of our scientific method, we gain data for teaching and publication. The Mohawks identified the research problem, provide the participants and the data in exchange for usable knowledge to inform their action about the adolescents and environment. They also contribute to the further development of our expertise in their sharing of information that is often personal and sensitive. There are many additional benefits that we share: jobs, skills for the future, and new friendships. Questions of equity also arise in such questions as who signs letters and reports to participants (we have a joint system), who authors papers and presentations (the current one provides an example), and who gives consent for findings to be published.

We have mentioned that the university and Akwesasne are almost five hours of driving apart, which creates a difficulty for regular meetings. We suggest that our practical solution of meeting approximately halfway at a lake named "Placid" also serves as a metaphor for our equitable collaboration.

Empowerment

Like respect and equity, empowerment is a two way process.

We are empowered by the knowledge, insights and sensitivities we gain to build our professional expertise. Moreover, in a very practical sense, our professional development, credibility and standing are furthered by the data made available for presentation and publication.

Our Mohawk research associates are also empowered by the professional training they gain for later independent work. Further, the Akwesasne Task Force on the Environment and the wider community will be empowered by our findings to plan appropriate environmental, educational and political action to remedy any situations our study finds to be problematic.

An important part of the project is community outreach and feedback to participants and the community. A problem with reporting back the results of PCB blood analysis to individual participants revealed conflict between the cultures of the Akwesasne community and the non-Native, bureaucratic world. The laboratory had the results, but was not certified to release them to the individuals who provided the specimens. Considerable time and rapport was lost in working through this problem; patience and optimism ultimately saved the collaboration.

Feedback about psychological functioning is provided to every participant. The school psychologists write a report for individual participants about their performance on the psychological tests. They meet individually with those participants who wish more detailed feedback or consultation about problematic situations. A procedure for referral to community and school agencies has been developed. Ongoing feedback is also given to the Task Force on the Environment about the functioning of the adolescents. When data for the full sample have been attained, results of the study will allow recommendations concerning environmental, dietary or school remedial actions which could improve the situation for the children and families in the community.

Ironically, the main contribution we make to community empowerment derives from holding firm to our central scientific role, namely that of providing good science. While the need for respect and equity sometimes demands compromise and accommodation, the central purpose of the collaboration requires that we generate data that is reliable and valid and thus speaks unambiguously to the community concerns. In order to provide such ecologically valid information, we must ensure that it stands up to external scrutiny, and contributes to understanding and application in the wider world.

Conclusion

Collaboration between the scientists and the Mohawk community has explicated and formalized issues that are present, even if masked, in all scientist-participant interactions. Sensitivity to relationships with the Native Americans makes us vigilant to respect other points of view. The prominence and formalization of the principles ensures, that while working towards comfortable interactions and routines, that comfort and routine will not be taken for granted, but must be actively worked for in every situation. The need for vigilance lest we trample on cultural values or trespass on cultural practices is not unique to interactions with Native Americans or even those who are affirming their differences. We are indebted to our Mohawk partners for providing the protocol principles that we have adopted as models for psychologist-client interactions in our applied psychological work (Rougas & Newman, 1998).

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